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AUTHOR	Brewer, Garry D.; Kakalik, James S.
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ABSTRACT

In remarks made to the 1974 Executives Conference of the Child Welfare League of America, the author summarizes a 2-year multidisciplinary study of U.S. programs and services for handicapped (specifically vision and hearing impaired) children and their families. Described are the study's first year efforts to identify the population, services required, programs, and delivery services. Considered are the second year's analysis of general system problems in four general classes: insufficient resources; inequity in access to services and level of services provided; gaps in such services as prevention, identification, and direction; and lack of planning, coordination, and information. Recommendations of important service needs include improvements in prevention, early identification, direction, and medical treatment. (CL)

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SERVING HANDICAPPED CHILDREN: THE ROAD AHEAD*

Garry D. Brewer
James S. Kakalik

August 1974

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Please note the following corrections to P-5304:

p. 2, line 5

"...Welfare." should read "Welfare, pursuant to contract HEW-OS-72-101."

p. 6, last of line of "Inequity" section

$168 or $2463" should read "$168 to $2463"

p. 6, last line

"of the 50" should read "of the more than 50"

p. 8, lines 9 and 10

"Titles III and VI B of the Elementary and Secondary Education Act..." should read "Title III of the Elementary and Secondary Education Act and Part B of the Education of the Handicapped Act..."

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SERVING HANDICAPPED CHILDREN: THE ROAD AHEAD

I. INTRODUCTION

More than 9 million mentally or physically handicapped children and youth in the United States aged 0 to 21 are impaired enough to need services not required by their "normal" counterparts. There are currently over 50 different major federal programs and hundreds of state and local programs, which together expended nearly $5 billion annually in recent years to provide a wide variety of services to mentally and physically impaired children.

There is no question, the current service system is very worthwhile; indeed, portions of it are outstanding. However, many major problems face the system, and with better organization and support it could do far better. Many youth are not receiving services, or they are receiving the wrong or inadequate services; extreme inequities prevail in the delivery of services; there are serious gaps in services offered; information is insufficient, control is inadequate, and most important, the resources devoted to serve our handicapped children in need are insufficient.

To understand the kinds, magnitudes, and interrelationships of problems requires that we view both from a comprehensive service system perspective and from the perspective of the basic service needs of the youth. In other words, what does the current system "look like" from different important points of view? To mount any large-scale effort to improve services to these youngsters requires that we consider an array of objectives from the modest to the most ambitious, taken in terms of the child's basic needs. In other words, knowing approximately where we are, where do we want to go, and what are some "roads" to get there?

II. AN OVERVIEW OF RAND'S STUDY EFFORT

At best the comments that follow are the briefest of summaries of an extremely detailed, two-year, multi-disciplinary research effort that we and numerous other Rand Corporation colleagues undertook at the request of the Assistant Secretary for Planning and Evaluation of the U. S. Department of Health, Education, and Welfare. Accordingly, we strongly encourage anyone sharing our concern for these topics to consult our two Rand Corporation research reports for a full accounting.*

Because of the fragmented nature of the current system, when we began it was an open question what the overall system either looked like or did: How many were being served? What services were delivered? At what cost? Answers to these simple questions were not known, let alone answers to questions about the effectiveness of the system's operation. Beginning to answer these questions turned out to be a challenging undertaking, but to understand service problems and to make recommendations for service improvement, the current "base-case" service system had to be detailed.

Topical elements comprising the "base-case" are summarized as follows:

- The handicapped youth population: determined according to the age, type and degree of handicap, and several other factors.
- The services needed by the population: prevention of handicapping conditions, identification of handicaps, direction to appropriate service providers, counseling, medical treatment, sensory aids and other equipment, education, vocational and special training, job placement, recreation, personal care, income maintenance, training of personnel to supply the services, construction of facilities, and research.

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*James S. Kakalik, Garry D. Brewer et. al., *Services for Handicapped Youth: A Program Overview* (Santa Monica, Cal.: The Rand Corporation, R-1220-HEW, May 1973); and *idem, Improving Services to Handicapped Children* (Santa Monica, Cal.: The Rand Corporation, R-1420-HEW, May 1974). Both are available from The Rand Corporation, 1700 Main Street, Santa Monica, California, 90406.

- o The programs making up the current system.
- o Information, within the limits of available data, on the institutional structures, service delivery mechanisms, resources devoted to classes of handicapped youth, and related problems.

The first year's work resulted in a description of the service system's present, or base-case form, for all types of handicapped youth. It is impossible to detail the base-case, given the limitations of this conference's proceedings. However, let us note that we made extensive efforts to pull together the bulk of existing information on the system; we took different points of view of the system, including that of federal, state and local officials, of other service providers, and of the handicapped population itself; and we honestly admitted those instances where important information either did not exist or where we had not been able to procure it.

In the second year, we concentrated on a list of problems generated by our analysis of the base-case--a long list including system problems, management problems, logical problems, and priority problems. Before characterizing these problems, let us stress the points that in general the current system and the programs that comprise it are very beneficial; the individuals involved in delivering these services and administering the programs are typically dedicated, hard-working, and thoroughly professional. However, partly because the system itself usually is neither viewed nor managed from a comprehensive perspective, we find many major problems in need of attention and resolution. In short, the nation is doing a creditable job of serving its handicapped children, but with better attention to the overall system and more effort, the job--in our view--could be done much better. Our second year's effort did not focus on all types of handicapped youth, but rather was concentrated on developing recommendations for improving services to hearing and vision handicapped youth.

Our recommendations range from termination of some programs to consolidation and expansion of others, and from improvements in the management and structure of service programs to shifts in the mix of

services provided. Because current service problems and policies generally apply to all types of handicapped children, many of our recommendations, if adopted, would result in improved services for all types of physically and mentally handicapped children, as well as for those with sensory handicaps.

III. A SUMMARY OF GENERAL SYSTEM PROBLEMS

The problems we identified may be summarized into four general classes according to potential system objectives that one concerned about handicapped children might have in mind.

- o Insufficient resources
- o Inequity
- o Gaps in services
- o A lack of planning, coordination, and information

Let us repeat, subsumed within these four general classes are dozens of specific instances documented in our reports. What follows is at best a thumbnail sketch of those findings presented mainly for illustrative purposes. We strongly encourage readers to refer to our complete work for a detailed treatment of these quite complex issues.

Insufficient Resources

Insufficient resources is a problem if one of the objectives is to serve all of those who are eligible and in need. Presuming that this is so, then it is a major problem. Roughly, if one wants to meet the needs of the current young handicapped population, it means that there must be *at least* a doubling of the current $4.7 billion annual expenditures from all sources. While one can quibble over the precise dollar value, the logic of the argument that expenditures must be at least doubled to serve all those in need is simple and clear. We considered sixteen different services in our study, but let us take just one here for an example. Special education accounts for some $2.68 billion of the total annual service bill. However, by the most conservative estimate, something less than 60 percent of those eligible and in need of special education are currently receiving it; in other words, about 2 million handicapped children who need and could benefit from special education are not receiving it and the added cost to provide that special education alone is approximately $2.5 billion per year.

In the near term, of say the next five years, there are several strong indications that a proportion of this resource gap will be filled, e.g., "right to education" court rulings being handed down in many states and provisions contained in recent federal special education legislative proposals (HR 70 and S 6). We encourage these and related initiatives, but we are also concerned that many other, less-costly changes having long-term payoffs may not be given sufficient attention. Prevention and vocational rehabilitation are only two such examples, and several others will be noted momentarily.

Inequity

Inequity is a problem if one of the objectives is to provide children having similar problems in equivalent circumstances with similar services. Provision of such similar services is not presently the case, and to the extent that it is not, inequity is a major problem.

There is inequity in both a child's access to services and the level of services provided. For example, in a generally commendable vocational rehabilitation program, we found that for all handicapping conditions a 5-to-1 discrepancy existed in per capita expenditure between the most and least generous states; and for deaf youth this figure increased to 20-to-1. In special education, to cite another example, the percent of all handicapped youth served varies from 20 to 90 percent across the states; for various classes of handicaps, this same figure ranges from about 25 percent for hearing handicapped and emotionally disturbed to about 75 percent for the speech impaired. Computed on a simple per capita basis, special education expenditures varied across the states for all handicapped children from $168 or $2,463 per annum.

Gaps in Services

Gaps in service provision is a problem if one of the objectives is to match a child's evolving needs with an appropriate mix of services. When we performed the simple exercise of cross-tabulating all of the 50

identified federal programs against our list of services a child or youth could require (e.g., Which of the 50 programs provide some amount of prevention, medical treatment, or special education?) we were surprised to find that three services are scarcely represented at all, either in dollar or program terms: prevention, identification, and direction.

Insufficient prevention implies that a handicap is treated "after the fact," and that some proportion of future handicapped children need not be. Inadequate identification means that some number of children in need either do not receive services, receive the wrong services, or receive services later in life than would be optimal if concern were focused on early detection and remediation. Poor or nonexistent direction may mean that a child is not matched with the appropriate mix of services, if they exist locally, to the detriment of both the child and the effective operation of the system.

Other service gaps are more straightforward. Several states require their hearing handicapped and deaf children to travel long distances to special schools and thus provide the parents with a Hobson's choice: Separate the child from the family; move the family to be nearby the handicapped child's school; or do without often critically important services. This is not an idle rhetorical exercise; one-in-ten of a sample of families of handicapped children we surveyed had in fact recently moved just to get needed special educational services for their children.

Lack of Planning, Coordination, and Information

If one feels that programs should be guided by overall objectives, that duplication of programs is undesirable, and that adequate knowledge of what is going on, both within and between programs and services, is desirable, then these represent a distinct problem area.

Information about individual programs, the handicapped population, and the overall service system often is in disarray, of poor quality, or non-existent.

There is inadequate coordination at the federal level; there is no federal policy for services to handicapped children and youth. Objectives are often unclear, at cross-purposes, or nonexistent; in fact, it is accurate to portray the system in terms of different sets of objectives for each of the identified programs. Hopefully the newly created Office for the Handicapped will alleviate some of these problems. The issue of coordination is easily seen in the case of the Bureau of Education for the Handicapped which only handles about half of the federal share of the special education budget. Titles III and VI B of the Elementary and Secondary Education Act may fund the same type of projects, but there is very little coordination between bureaucracies administering each. The Crippled Children's Service and Medicaid both fund health care for needy handicapped youth, but coordination is slight between them.

Planning for each individual is inadequate. There almost always is no effective mechanism for matching the child's needs with the services locally available. The result is children who do not get some needed services or receive an inappropriate service.

Sketching out a few of the problems confronting those concerned with the health and well-being of our nation's handicapped children is not done to discourage anyone, although many of the specifics in the bill of particulars are far from pleasant. Rather, we view a careful detailing and documenting of problems as a necessary first step in formulating recommendations for improvement. To proceed from some point "a" to a desired point "b" on any map, one needs to know where the two points are located. Once this information is known, selecting alternative routes between the points can truly become a matter of rational choice--not a random walk through the unknown.

IV. A MAP OF THE ROAD AHEAD

Answering the question, "What do we want to do?" is analogous to selecting a trip's destination and route. Creating alternative renditions, or scenarios, of moving from point "a" to point "b" is, of course, similar to tracing out different combinations of highways and byways that all commence at "a" and end at "b." The critical tasks are, however, not nearly as simply performed as reading a map. Many of the pathways are fraught with uncertainty, some are clearly terribly costly, and many others may involve on-the-spot road, tunnel, and bridge construction. More importantly, the goals or desired destinations of social programs are not a single point on a two-dimensional map.

Multiple Objectives

Different groups have different goals which are generally only vaguely specified and many-dimensional, consisting of sometimes conflicting concepts of resource limitations, equity, and future quality-of-life and economic effects.

Do you want to develop the maximum potential of every child? If so, are you talking about a variety of components of a child's potential, such as sensory, motor, and intellectual ability, social independence, and economic nondependency, or some alternative set of components? Are you going to look at the problem in terms of increasing the future economic benefits that accrue to society? Are you going to concentrate on limiting short-run costs, either to the exclusion of all else or while trying to do other things simultaneously, such as enhancing the long-run quality of life for the handicapped child or economic benefits for the society? Or, should you work diligently to increase the equity of services provided, while placing lower emphasis on other plausible and desirable objectives?

The answers to these questions are not readily or easily determined; furthermore, the questions themselves are seldom so starkly framed.

Some of the More Important Service Needs

Earlier, three important concepts were touched on: The level of effort that one, presumably the government, might be willing to expend, the service needs of the population of handicapped children and youth, and some service objectives for that population. Concentrating on these, our full report presents a wide variety of recommendations dependent on the level of effort one chooses to make and on one's objectives. In the limited time available here we will only discuss some of the more important service needs of handicapped children. Beginning with the ordering of service needs according to the age of the population and stage of the handicapping condition, we arrived at some interesting, non-obvious findings.

Prevention, identification, and direction are three underdeveloped services which taken together account for no more than 3 percent of the total current annual expenditure for the population. Not only are these three services underdeveloped, but they possess nice logical properties which enhance their overall attractiveness.

To prevent as many potential handicaps as possible fosters several of the basic objectives previously specified. Assuming that increased preventive effort is expended, the next most-pressing service need is identification, e.g., find and correctly diagnose as many potentially handicapped youngsters at as early an age as possible.

Several arguments follow from this. Many handicapping conditions, particularly sensory disorders, are amenable to treatment, and if treated properly at an early age, often yield excellent prognosis for little or no residual impairment. The best medical care in the world, which our nation possesses in large measure, is relatively useless unless a youngster in need is found, diagnosed, and directed to it in sufficient time to correct or alleviate a possibly handicapping condition. Most of our children receive no hearing and vision tests until they are about to

enter elementary school--often later than an optimal time in their lives to correct potentially handicapping sensory disorders--and even at age 5 or 6, over half of our children do not even receive a vision or hearing test. There is no systematic means by which all children are screened and those possessing potentially handicapping conditions identified at an age when remedial medical care and other types of services have the best chance of doing the child the most good. Furthermore, to improve identification efforts would help realize several of the objectives previously noted, including helping develop the child's maximum potential and quality of life, increasing future societal economic benefits, and increasing the equitability of services delivered.

Direction, another underdeveloped service, is important for both present and future handicapped children. For those already impaired, proper direction offers the hope of making good matches between what a child needs at various stages in his life and what is locally available to improve that child's life. For future generations, direction--if carefully and thoughtfully implemented--could provide a critical missing element in the current service system: information at the local level which, when appropriately aggregated to the state and federal levels with privacy controls, would supply many missing facts needed to control and build the service delivery system effectively. Direction, as we conceive it, has many desirable prerequisite properties for increasing the amount and quality of information about the system which, in time, may be converted into better understanding and improved management and service control.

Presuming that improvements are made in the underdeveloped services of prevention, identification, and direction, a next logical service to focus on is quality medical treatment appropriate to the child's needs. Our nation's medical treatment system is in many respects magnificent; however, we use it inefficiently by ignoring the prior, underdeveloped three services of prevention, identification, and direction for handicapped children.

Presuming that the levels of effort in prevention, identification, direction, and medical treatment have been increased as much as desirable, it next makes sense to fit a child with a prosthetic device or sensory aid if needed to reduce the extent of residual handicapping to the greatest extent possible before trying to special educate or vocationally rehabilitate him or her. In the currently fragmented service system, this simple logic does not always hold. Many children are receiving sensory aids, for example, but without benefit of a prior medical examination. Much interesting and potentially beneficial research has not been translated into operational, tested, evaluated, and accessible devices. Saddest of all, despite occasionally high, but one-time, costs, something on the order of half of the children who need and could benefit from a sensory aid in fact have none.

Even if all prior services have been created and expanded, there will still remain a residual population of impaired children. For them, "right to education" judgments are beginning to dictate long overdue improvements in special education services. Our concern and arguments to this point are not intended to undercut these demands and initiatives for improved special education; quite the contrary, our interest is to reduce to a minimum the total population who will need these traditionally expensive services and, having done so, to provide the finest special education government is willing to pay for (a level-of-effort decision) to those who still need it. Recall, by conservative estimates, providing special education to those currently in need and eligible, but who do not receive it, would cost about $2.5 billion more each year. Would it not be prudent, so goes the logic of this argument, to increase the levels of effort for services we discussed earlier in hopes of reducing the total population and the general severity of handicapping before or concurrent with expansion of special education? The argument is convincing, once made, but still surprisingly novel to many who are deeply involved in doing "something" for the current population of handicapped--but doing it in compartmentalized, fragmented programs

without benefit of a more comprehensive and longer-range view of the problem.

When a handicapped child finishes with his formal school career, he must enter adulthood; vocational training is one important way of preparing the youth to do so. Not only is vocational habilitation important from the handicapped adolescent's point of view, but it can be demonstrated to be--even under very stringent constraints and assumptions--cost-effective from society's point of view.

Even if the nation increases its efforts in all the service areas already mentioned, and realizes reductions in the number and severity of handicaps among our children by doing so, there will still remain an unfortunate subset of the population who will require income maintenance in their adult years. Thus, a wide spectrum of services is needed to serve the widely varying needs of our nation's handicapped children. Given limited resources, a major question is what priority will be set for serving these children.

* * * *

This paper is the briefest of sketches of some of the points made in our extensive, comprehensive evaluation of programs and services currently available for this nation's handicapped children and their families. We strongly urge you to read and reflect on our complete work--as much for the improved understanding of specific details it will provide as for a better sense of the urgency of providing an improved service system for our nation's handicapped children.